

VS-MCS brochure authorship and acknowledgement:

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Acknowledgements: Funding for writing and publication of this brochure was provided by National Institute on Disability and Rehabilitation Research grant #H133A031713 (A Multicenter Prospective Randomized Controlled Trial of the Effectiveness of Amantadine Hydrochloride in Promoting Recovery of Function Following Severe Traumatic Brain Injury).

The Brain Injury Association of America (BIAA; www.biausa.org) provided feedback from the consumer perspective for the content of this brochure and is assisting with dissemination of these materials.

Several family members of persons with TBI generously gave their time and valuable insights to assist with the writing of this brochure.

Facts about the Vegetative and Minimally Conscious States after Severe Brain Injury



*A project funded by the
National Institute on Disability
and Rehabilitation Research*





SEVERE BRAIN INJURY causes a change in consciousness. Consciousness refers to awareness of the self and the environment. Brain injury can cause a wide range of disturbances of consciousness. Some injuries are mild and may cause relatively minor changes in consciousness such as brief confusion or disorientation.

The most severe injuries cause profound disturbance of consciousness. Twenty to 40% of persons with injuries this severe do not survive. Some persons who survive have a period of time of complete unconsciousness with no awareness of themselves or the world around them. The diagnosis given these people depends on whether their eyes are always closed or whether they have periods when their eyes are open. The state of complete unconsciousness with no eye opening is called **coma**. The state of complete unconsciousness with some eye opening and periods of wakefulness and sleep is called the **vegetative state**. As people recover from severe brain injury, they usually pass through various phases of recovery. Recovery can stop at any one of these phases.

Characteristics of coma

1. No eye-opening
2. Unable to follow instructions

3. No speech or other forms of communication
4. No purposeful movement

Characteristics of the vegetative state

1. Return of a sleep-wake cycle with periods of eye opening and eye closing
2. May moan or make other sounds especially when tight muscles are stretched
3. May cry or smile or make other facial expressions without apparent cause
4. May briefly move eyes toward persons or objects
5. May react to a loud sound with a startle
6. Unable to follow instructions
7. No speech or other forms of communication
8. No purposeful movement

Persons in coma or vegetative state require extensive care that may include:

1. Feeding using a feeding tube
2. Turning in bed to prevent pressure sores
3. Special bedding to help prevent pressure sores
4. Assistance with bowel and bladder relief using catheter and/or diapers

5. Management of breathing such as suctioning of secretions; this may include care for a tracheostomy tube
6. Management of muscle tone (excessive tightness of muscles)
7. Special equipment that may include a wheelchair or special bedding to help with proper posture and decrease muscle tightness
8. Management of infections such as pneumonia or urinary tract infections
9. Management of other medical issues such as fever, seizures, etc.

What happens after coma and vegetative state?

When people start to regain consciousness, they may:

1. follow simple instructions from others such as, “Open your eyes,” “Squeeze my hand,” “Say your name,” etc.;
2. communicate by speaking words or by indicating yes or no by head nods or gestures; and/or
3. use a common object in a normal way such as brushing hair with a brush, using a straw to drink, holding a phone to the ear, etc.

Persons with brain injury transition through the period of unconsciousness and subsequent stages of recovery at a slower or faster rate, largely depending on the severity of injury. Those with less severe injuries may transition through these stages more

As people recover from severe brain injury, they usually pass through various phases.

rapidly and some of the stages described here may be poorly recognized or not occur at all. Those with very severe injuries may stall at one or another stage and not be able to make the transition to a higher level of recovery.

For persons with more prolonged periods of unconsciousness, emergence from unconsciousness is a gradual process. Coma rarely lasts more than 4 weeks. Some patients move from coma to the vegetative state but others may move from coma to a period of partial consciousness. It would be very rare for a person to move directly from coma, or vegetative state, to a state of full consciousness.

Persons who have shorter periods of unconsciousness likely had less severe brain injuries initially. Consequently, they are likely to go on to make better recoveries than persons who had longer periods of unconsciousness.

Traumatic brain injury refers to damage to the brain caused by external force such as a car crash or a

fall. About 50% of persons who are in a vegetative state one month after traumatic brain injury eventually recover consciousness. They are likely to have a slow course of recovery and usually have some ongoing cognitive and physical impairments and disabilities. People in a vegetative state due to stroke, loss of oxygen to the brain (anoxia) or some types of severe medical illness may not recover as well as those with traumatic brain injury. Those few persons who remain in a prolonged vegetative state may survive for an extended period of time but they often experience medical complications such as pneumonia, respiratory failure, infections, etc. which may reduce life expectancy.

People who have a slow recovery of consciousness continue to have a reduced level of self-awareness or awareness of the world around them. They have inconsistent and limited ability to respond and communicate. This condition of limited awareness is called the **minimally conscious state**.

Characteristics of the minimally conscious state

1. Sometimes follows simple instructions
2. May communicate yes or no by talking or gesturing
3. May speak some understandable words or phrases

4. May respond to people, things, or other events by:

- crying, smiling, or laughing;
- making sounds or gesturing;
- reaching for objects;
- trying to hold or use an object or
- keeping the eyes focused on people or things for a sustained period of time whether they are moving or staying still

People in a minimally conscious state do these things inconsistently. For example, one time the person might be able to follow a simple instruction and another time they might not be able to follow any instructions at all. This makes it difficult to distinguish the vegetative state from the minimally conscious state.

While in a minimally conscious state, people need extensive care similar to that needed by people in a vegetative state.

Emergence from the minimally conscious state

Once a person can communicate, follow instructions, or use an object such as a comb or pencil consistently, they are no longer in a minimally conscious state. Some people remain minimally conscious indefinitely, but many improve. The longer a person remains in a minimally conscious

Comparison of Coma, Vegetative State, and Minimally Conscious State

	Coma	Vegetative State	Minimally Conscious State
Eye Opening	No	Yes	Yes
Sleep/Wake Cycles	No	Yes	Yes
Visual Tracking	No	No	Often
Object Recognition	No	No	Inconsistent
Command Following	No	No	Inconsistent
Communication	No	No	Inconsistent
Contingent Emotion	No	No	Inconsistent

state, the more permanent impairments he or she is likely to have. This is because vegetative and minimally conscious states are caused by severe damage to multiple brain areas. Following emergence from the minimally conscious state, people almost always experience confusion. Sometimes people move directly from coma to this confusional state.

Characteristics of the confusional state

1. Disorientation (inability to keep track of the correct date and place)
2. Severe impairment in attention, memory and other mental abilities

3. Fluctuation in level of responsiveness
4. Restlessness
5. Nighttime sleep disturbance
6. Excessive drowsiness and sleeping during the day
7. Delusions or hallucinations

As with the vegetative and minimally conscious states, the rate and extent of recovery from the confused state vary from person to person. However, almost all people who reach the confused state go on to make further progress. The main factors that

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determine the eventual degree of recovery are the initial severity of the brain injury and some types of additional medical problems. The shorter

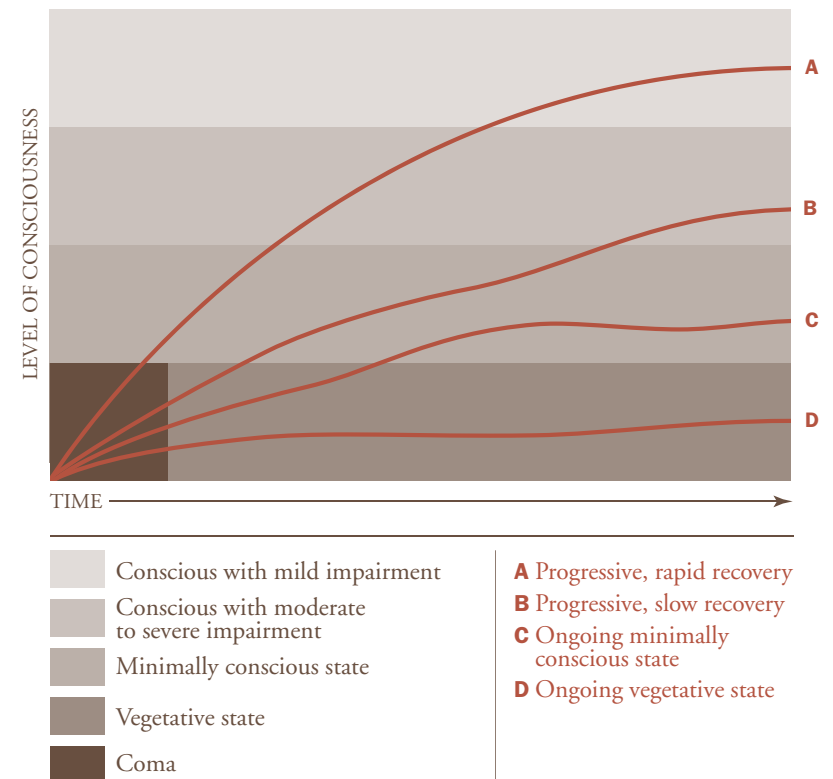
the time the person is in the confused state, the better the eventual recovery will be. Mild medical complications such as sleep disturbance or urinary tract infection may prolong the confused state but do not necessarily influence the final outcome.

Once the confusional state resolves, people are usually much better able to pay attention, orient themselves to place and time, and retain memories for day to day experiences. Nevertheless, they are very likely to have some significant cognitive problems such as impaired memory or slowed thinking. These cognitive problems are likely to continue to

improve as time passes. Some people make limited progress, while others make a good deal of progress.

Patterns of recovery after very severe brain injury

This image shows some patterns of recovery that follow emergence from coma. Some individuals rapidly emerge from coma and briefly remain in the minimally conscious state before recovering a higher level of consciousness with mild impairments. Others may have a longer period in the minimally



conscious state after emerging from the vegetative state and then usually have a greater degree of long-term impairment. Occasionally, persons remain in the vegetative or minimally conscious state for an extended period of time and, in rare cases, these conditions may be permanent.

What treatments are used with people in the vegetative or minimally conscious state?

Currently, there is no treatment that has been proven to speed up or improve recovery from the vegetative or minimally conscious state. However, there is general agreement that the primary focus of medical care is to prevent or treat any factors that might hinder recovery (such as hydrocephalus, a

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build up of fluid on the brain, or use of sedating drugs for other conditions), and to preserve bodily health

(such as treating infections or stiffness of joints). Medical facilities and clinicians vary in the extent to which they try various treatments such as medications or sensory stimulation to promote recovery of consciousness. Because the amount of recovery from disorders of consciousness varies so greatly, it is difficult to judge the value of these and other treatments outside of research studies. You can

inquire about your physician or program's philosophy about using these types of treatments.

Transitions to different levels of care

At various points in the process of recovery, persons in the minimally conscious or vegetative state may receive care in a wide range of settings. Initially, the person with severely impaired consciousness is most likely to be treated in an acute care hospital where the focus is primarily on saving his/her life and stabilizing him/her medically. Once that is achieved, the next focus is on recovery of function to whatever level is possible. Sometimes this happens in an acute rehabilitation hospital, which provides a high intensity program of rehabilitation services, including physical therapy, occupational therapy, speech and language therapy, recreational therapy, neuropsychological services and medical services.

Some patients do not transition from the acute care hospital to an acute rehabilitation program. These people may go directly to a skilled nursing facility, a sub-acute rehabilitation program, a nursing home, or even home with family. Persons discharged from an acute rehabilitation program usually go to one of these places as well. Skilled nursing facilities, sub-acute rehabilitation programs, and nursing

homes vary widely in the quantity and quality of medical management, nursing care, and rehabilitation therapy services they provide.

MANY FACTORS INFLUENCE DECISIONS about where a person with severe impairment of consciousness or other severe impairments may go after discharge from the acute care hospital or discharge from the acute rehabilitation program. Some of these factors are the person's medical condition, health insurance coverage and

It is helpful to work with a social worker or case manager in the facility where your loved one is currently receiving services

other benefits, the person's ability to tolerate rehabilitation therapies, the doctor's philosophy about where people should go to continue to recover after severe injuries, the family's ability

to care for the person at home, the family's wishes, and practical matters such as that the distance the family has to travel to visit the person at the facility.

The names used to describe levels of care and the settings in which they are provided, vary across the country. It is helpful to work with a social worker or case manager in the facility where your loved one is currently receiving services to plan whatever transitions are necessary. Do not be afraid to ask

questions to make sure that you obtain the information you need to help you make the best possible decision.

Things to look for when considering a setting to care for your loved one:

At various points in the process of recovery, persons in the minimally conscious or vegetative state may receive care in a wide range of settings. These include in-patient rehabilitation facilities, skilled nursing facilities, and long-term acute care facilities. The following are some considerations for selecting a place for care:

1. Your family member's current treatment team has had good experiences with the program when they have referred others there.
2. The staff at the facility makes you feel comfortable, is accessible to talk with about your concerns, and answers your questions.
3. The program and medical staff have experience working with the same kinds of problems that your family member has.
4. The facility is informed about the specifics of the care your loved one needs and is able to meet these care needs. You can have a role in ensuring that a detailed nursing plan of care is developed.

5. The program includes case management to assist in planning for the next level of service, whether it is transition to a rehabilitation program, a facility for long-term care, or home.
6. The program provides education and training for future caregivers.
7. The program uses specific procedures to measure progress.

If support services can be arranged, some persons in the minimally conscious or vegetative state can be cared for at home.

Thoughts from families who have been there

Family members who have a loved one in a minimally conscious or vegetative state have identified a number of important issues:

1. *Communicating with healthcare providers*
Be sure to ask questions, share your observations, and express your opinions.
2. *Managing medical equipment and supplies*
It is important to be knowledgeable about your loved one's equipment and supplies, and know how to communicate with the companies who provide these items.
3. *Providing care*
Family members often provide some of the care

for their loved ones. The amount of care you provide will depend on your role in providing care (this can range from providing most of the care yourself to simply directing the care provided by others), the people such as sitters, attendants, nurses, and family members who are available to help you with providing care, the setting (this could be your home or a skilled nursing facility), and the guidance you receive from health care providers. It is desirable to obtain as much training as possible to provide whatever elements of care you chose to provide and are able to manage. These might include bathing, grooming, bowel and bladder management, mobility, range of motion, and other medical issues that your loved one may have.

4. *Learning about financial resources*
You may initially feel overwhelmed when you start to learn about various financial resources that may be appropriate for your loved one. However, with patience, persistence, and some help from others, you will be able to figure out which programs apply and find your way through the application processes.

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Programs you will want to learn about include:

- Healthcare programs such as Medicare and Medicaid.
- Income replacement or financial assistance programs such as SSDI (Social Security Disability Insurance), SSI (Supplemental Security Income), or possibly disability insurance policies that your loved one may have had through work.
- Services to help with community living such as state agencies that assist people in these areas.

It might not be possible to find someone who knows everything about how to access these various services and programs. The key is to

The most natural way of interacting is to talk to your loved one, even though he or she may not respond or understand.

keep asking questions and following up to make sure that you and your loved one get all the benefits that are available. People who

may be helpful to you are social workers, therapists, case managers, the local social security office, your state brain injury association chapter, family members or friends who are disabled or who have family who are disabled, or the human resources (personnel) department at your loved one's employer.

5. *Guardianship*

Since your loved one is not able to fully make decisions for himself or herself, it may be helpful for you, or someone else, to be appointed guardian. This may make it easier to handle medical decision making or management of your loved one's financial matters. If you think that your loved one may need to have a guardian appointed, you will need to contact an attorney to get assistance. Guardianship can be reversed when it is no longer needed.

How to interact with your loved one who is unconsciousness or at a low level of responsiveness

The most natural way of interacting is to talk to your loved one, even though he or she may not respond or understand. Simple things like telling him or her about recent events in your life, what is going on in your family or neighborhood, or the latest news might make you feel a sense of connection. Talking with your loved one about what you are doing as you provide care can increase your comfort with the process of care giving. For example, telling your loved one that you are going to move his or her arms and legs to help prevent joint tightness might make you feel more comfortable with this task. Only do this "range of motion" type

activity if you have been instructed to do so by the doctor, nurse, or therapist.

Physical touch is another way of having a sense of connection. Some family members have said that the act of giving a massage or applying lotion to the hands or face helps them to feel close to their loved one. It is also important to avoid the risk of overstimulation as this may result in rapid breathing, tightening of the muscles, grinding of the teeth, restlessness and fatigue.

Taking care of yourself and other family members

Family members of a person in a vegetative or minimally conscious state often feel a sense of loss or grief for the relationship they had prior to the injury. There can be a number of ways to cope with these feelings. A person in a minimally conscious or vegetative state may make very slow progress or go for periods of time with no apparent progress. Sometimes keeping a journal of the changes you have observed may be comforting. This may give you a chance to look back and see ways in which he or she is more able to respond than he or she was at an earlier point in time.

Having a loved one who is in a vegetative or minimally conscious state can be physically and emotionally draining. Managing this alone can be

too much to ask of one person. It is important to rely on support from others, looking to existing supports and developing new ones. You might find help from supports you have relied on in the past, such as family, friends, and religious groups.

OTHER RESOURCES TO CONSIDER include support groups, support agencies, and the Internet. A good way to learn more about these possible supports is to make a contact with the Brain Injury Association of America's National Brain Injury Information Center (www.biausa.org, 1-800-444-6443) and obtain contact information for the closest state brain injury association (BIAA) chapter. Health care providers such as doctors, therapists, social workers and others can be good sources of information about supports available to you.

Even the most committed caregiver needs to have some private time. If your loved one is at home, this can range from having a friend or family member give you a 2 hour break to go do something for yourself to having full time caregivers for a week or having your loved one spend a brief time in a nursing care facility or hospital. If your loved one is still in the hospital or living in a nursing care facility, having a rotating visitation schedule can give you some breaks while giving other friends and family a chance to spend time with him or her.

When your loved one was first injured you were likely to be in crisis mode, focusing on the problems and putting the rest of life on hold. As time goes by, you will need to shift from crisis management

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mode, and begin to take care of the concerns of everyday life such as paying bills, maintaining relationships with other family members, and taking care of your own physical and mental

health. While it is natural to focus on your injured loved one, other members of your family will have needs too. For some people, formal counseling with a therapist or member of the clergy can be an important part of making adjustments to life changes that have occurred as a result of your loved one's injury.

While caring for a person in a vegetative or minimally conscious state is an enormous challenge, use of appropriate resources, as described above, can be a big help. Each person will respond differently to this challenge, but almost everyone can cope and move forward. Many family members have a deep sense of personal satisfaction in making life as comfortable and pleasant as possible for a loved one who has sustained a severe injury.

